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ABSTRACT

The paper describes a respite care cooperative in Orange County, California in which parents of handicapped children help other parents by providing a break from continuous care. The model features ongoing training and no cost for services. Goals and principles of the program are delineated, and procedures regarding such aspects as application process, confidentiality, first aid requirements, insurance, job descriptions, meals, and recordkeeping are noted. Parents earn respite time for themselves by providing respite to other families. Appended materials include an example of a respite ledger, discussion of first aid training, and sample respite forms. (CL)

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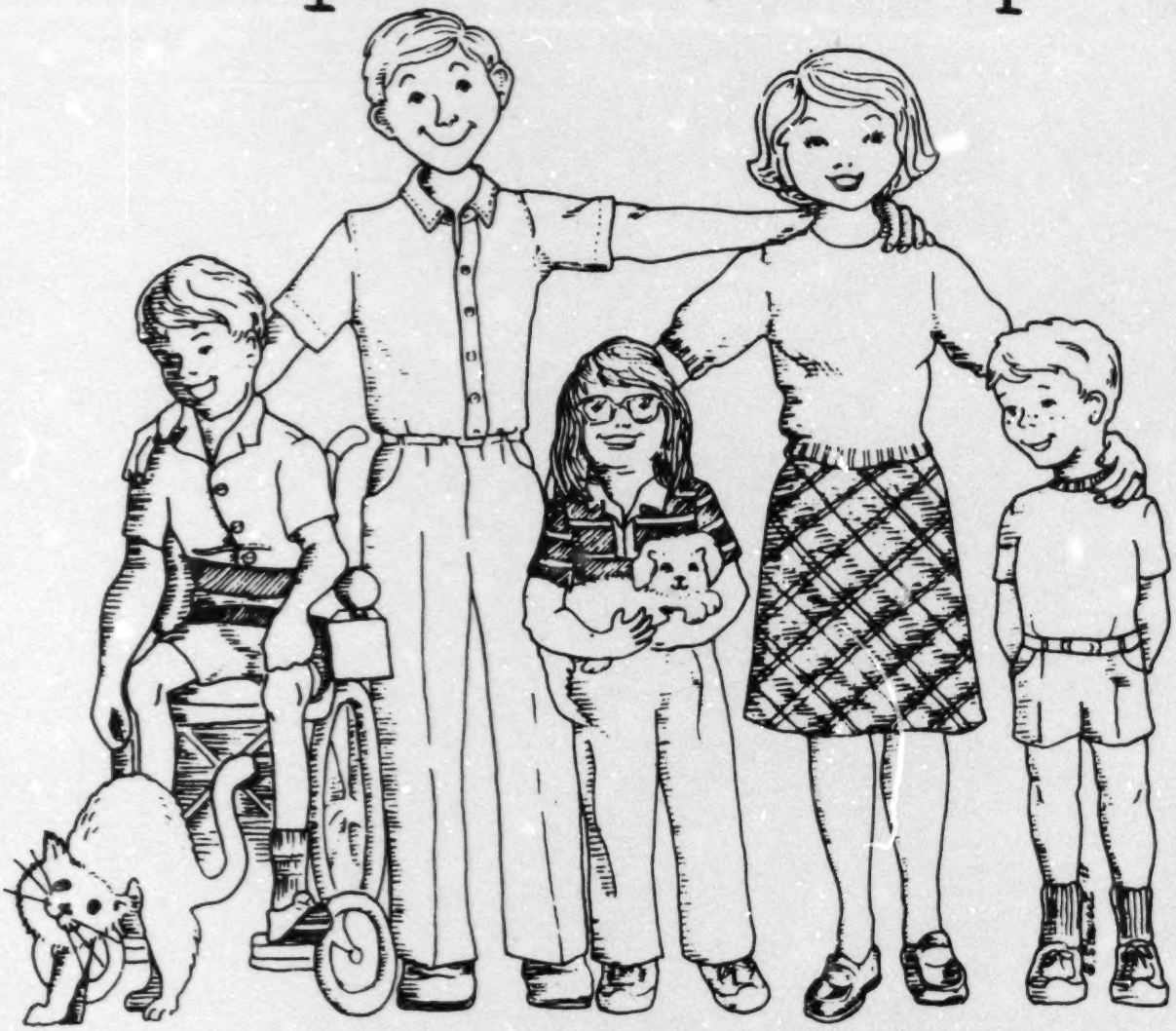
A Parent's Guide to the Easter Seal Society Respite Care Co-op



by Lorraine E. Shaw
and Tonya D. Gallegos

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A PARENT'S GUIDE TO THE EASTER SEAL SOCIETY RESPITE CARE CO-OP

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FORWORD

"It takes a man or woman with an out-of-the-ordinary commitment to volunteer for respite care, and such a person can give the family a psychological boost in addition to caring for the disabled member. This psychological reinforcement is amplified when the volunteer is also the parent of a disabled individual,"(1981, United Cerebral Palsy, New York).

ACKNOWLEDGMENTS

We, at the Easter Seal Society Orange County Regional Office would like to thank both the City of Orange and the Regional Center of Orange County Inc. for their financia. support of this program. We would also like to personally thank the members of the task force for their tremendous contribution and support.

THE EASTER SEAL SOCIETY
ORANGE COUNTY REGIONAL OFFICE

MISSION STATEMENT

Every special child and adult has a unique and individual potential- physical, emotional, and social. Each deserves the opportunity to develop this potential through direct services and community-based programs. We exist in order to provide belonging for those who need to belong, care for those who need care, incentive for those who need incentive, achievement for those who need to achieve.

THE RESPITE CARE CO-OP:

We exist in order to offer parents of children with special needs regular respite opportunities for rest, relaxation, or time alone to attend to personal needs; as well as to provide support during times of stress or crisis.

Chapter 1

Respite Care

CHAPTER ONE

RESPITE CARE: "YOU DESERVE A BREAK TODAY"

Respite is a term people generally are not familiar with. It is a term which means "time-off" or temporary relief. Respite is described as a system of temporary support for families with an individual who has special needs, which provides the family with a break from the continuous care for that individual. Temporary can mean care periodically or regularly. It can be for one hour to go grocery shopping, for an evening to enjoy a movie, or maybe for a whole weekend away.

Parents of children with special needs are able to receive a break from parenting in many forms which may not be perceived as respite. When they send their child to school, they receive respite. When they send them to summer camp for a week, they definitely receive respite. Respite is simply providing parents a break in the day-to-day care of a family member.

Respite is one service that can be utilized by all families regardless of the child's age or disability. For those families with young children, respite can act as a pressure valve providing temporary relief until the proper coping skills can be developed. Parents of premature and medically-fragile infants are a prime example because of the tremendous amount of unusual stress they often experience.

For families with school-age children, respite is convenient for parents who work and cannot pick up their child from school

or be home in the early afternoon. Also for many teenagers and adults, respite care may offer a way for them to be more independent. These individuals usually have limited opportunities for normal socialization and respite can help increase these chances.

Respite services can be modified to meet the needs of an even larger population. Children with serious illnesses such as cystic fibrosis, arthritis, diabetes, etc. are ideal candidates for respite programs, as are the elderly. This is usually because they require well-trained and qualified caregivers.

Parents of children with disabilities sometimes fail to allow themselves to be free of the responsibilities and awesome burdens of raising their children. One of the best things any parent can do for his/her child is to be rested and refreshed. Jordon (1975) has written a bill of rights for parents of children with special needs to insure these parents some freedoms in today's society (see appendix).

Spending time away is an event which requires parents to do a great deal of pre-planning and preparation. Often what occurs is that they are unable to prearrange "conventional babysitting" which can meet the unique needs of their special child. The parents are then forced to change their plans, thus not receiving the needed time-off.

It's important for parents not to become overburdened without any means of relief. Soon they may not be able to cope with the special needs of their child. Respite services are unique because they are designed exclusively to help the caregiver. Most

Chapter 2
Respite Services

CHAPTER TWO

RESPITE SERVICES: "OH, WHAT A RELIEF IT IS"

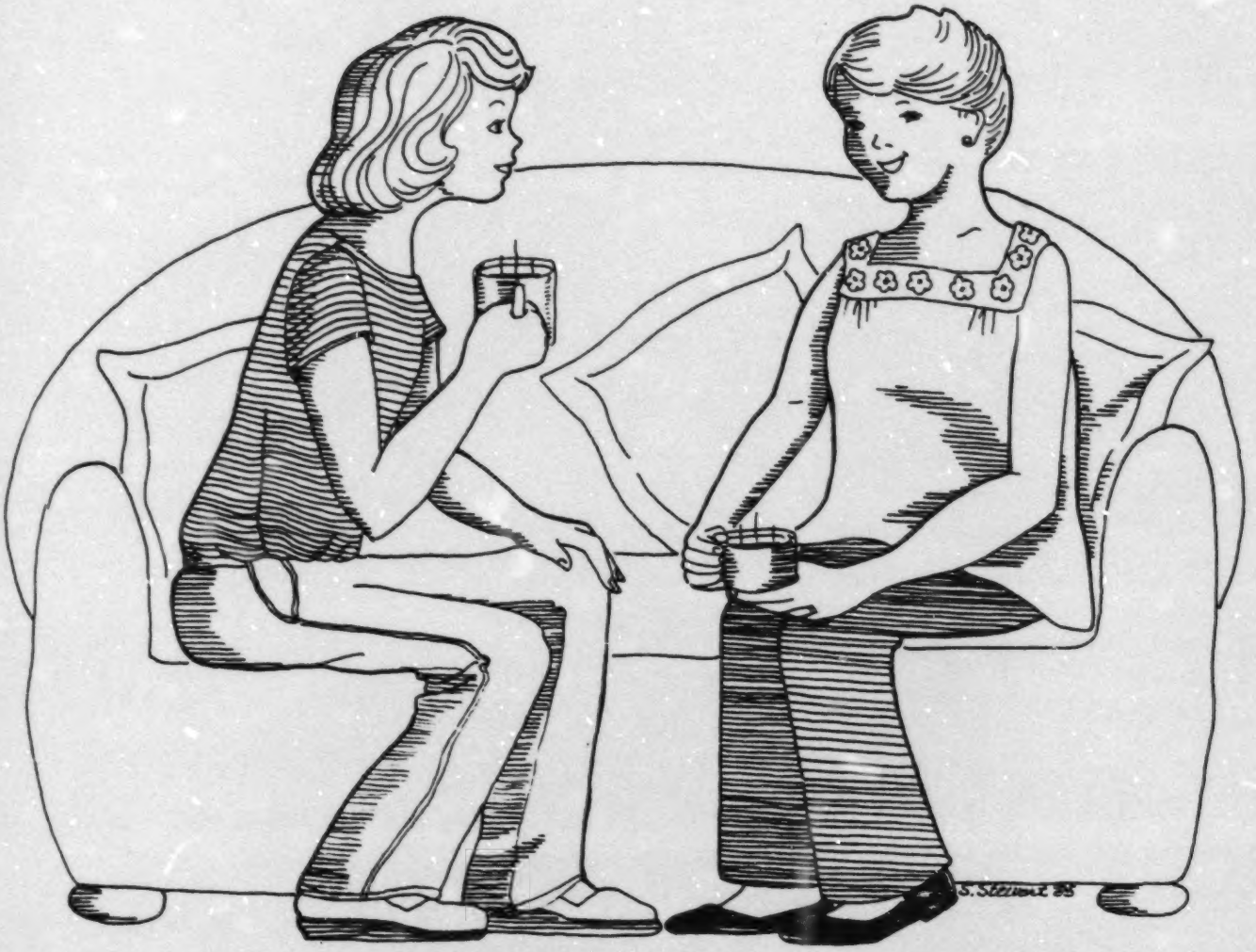
Respite programs generally come in many different models which vary widely in content, clients served, and cost. Most agencies, communities, and individual families discover one or two models which best suits their needs and is usually more economically feasible for them.

Some of the alternatives to choose from include; Extend or Host-a-Family programs which are staffed by volunteers, agency sitter/companion programs which require a fee, recreation programs such as summer day camp and field trip programs, and respite group homes.

Most families usually find one or two of these choices available to them in their own community. Here in Orange County the demand for respite programs exceeds the supply. There are a few agencies providing respite services, yet the needs are so great and diverse, there is much room for growth.

After a survey of community needs and input from parents and professionals, the Orange County Easter Seal Society decided to introduce a new and innovative respite model to the county; the Respite Care Co-op.

Chapter 3
The Respite Care Co-op



CHAPTER THREE

THE RESPITE CARE CO-OP: "THE PRICE IS RIGHT"

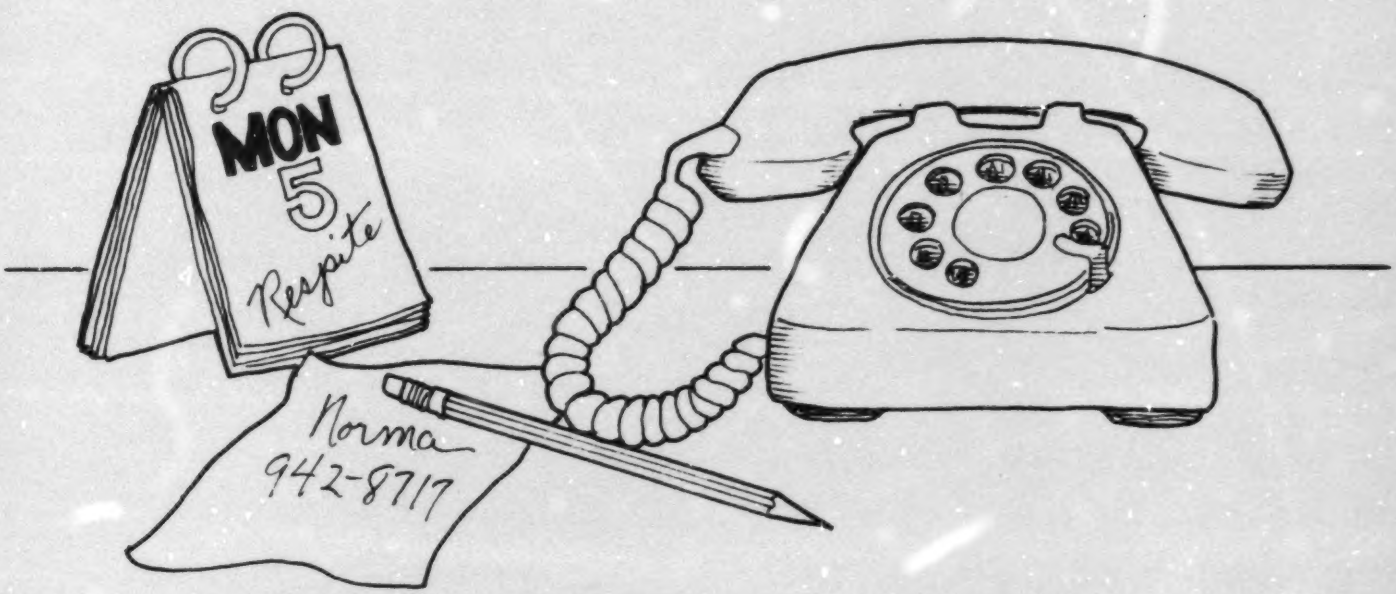
The theory behind the Respite Care Co-op is basic. Parents helping parents with respite needs. Families sharing similar needs, geographic location, and availability are matched together into separate Co-op groups of 5-10 families each. These families specifically train each other to care for their children then begin trading credit and debit hours of respite care. On-going workshop sessions and a parent's manual such as this one are also provided.

There are many benefits to the Respite Co-op model. One is that the concept is flexible enough to meet almost everyone's needs, whether it is used frequently or occasionally, by mild or severe clients. Another added benefit is if ever there was a crisis or emergency in a family, immediate and reliable care has already been prearranged. This allows the family to have up to 10 families to rely on.

One of the best advantages to the Co-op model, which makes it the most attractive to parents, is that there is no cost for this respite program. The care received is paid back by an equal amount of care given. In a large group of 10 families, the hours are evenly distributed among all the members. This eliminates the situation of just one or two families constantly being called upon. Families receive healthy, safe, reliable, and understanding care tailored for the specific needs of their child at no cost!

Also eliminated are the feelings of guilt and obligation usually associated with leaving a child with a babysitter. The family is assured they will not be indebted to another family because that family will also be paid back in an equal amount of respite time-off. Each requesting family has up to 10 families in any one Co-op to call upon when seeking respite care. Each family also is given the choice to say "no" when called upon if it is not convenient to provide respite at that time.

The following chapters include the principles and policies which were established by the task force for the Easter Seal Society's Respite Care Co-op.



Chapter 4
Goals and Principles

CHAPTER FOUR

GOALS AND PRINCIPLES: "YOU ARE IN GOOD HANDS"

GOALS

1. To allow parents and family members time-away for rest and relaxation.

2. To assist families through periods of stress and crisis such as illness, divorce, hospitalization, birth of a new baby, etc.

3. To help facilitate and extend hours of school and day care.

4. To help build support services and help increase long-term family stability.

5. To help increase the support and trust of families by parents helping parents.

6. To help people with disabilities increase their independence.

PRINCIPLES

A. Every family in Orange County who has a child with special needs is invited to register in the Easter Seal Society Respite Care Co-op to receive the time-off regardless of the degree or type of disability their child may have.

B. A Co-op will be established which best suits the individual needs of each family and if a Co-op does not exist then one will be created as soon as 5 families are recruited.

C. Each Co-op will be defined by geographic location and age rather than disabilities in order that parents have the opportunity to meet and share with other families whose children may not share the same disability.

D. Each family's highest priority is first to assist other families with respite care in order to receive respite care for themselves at a later date.

E. The Respite Care Co-op strives to simplify the lives of parents by remaining a simple concept without requiring many rules or regulations.

Chapter 5
Policies and Guidelines

CHAPTER FIVE

POLICIES AND GUIDELINES: "READY, SET, GO!"

Policies and guidelines for respite programs should have some flexibility due to the highly variable and individualized requests from families. However, policies should be formulated to give the consumers, professionals, and the rest of the community some idea of the program guidelines. These policies and guidelines which are stated below have been agreed upon by the task force and are placed in alphabetical order for easy reference.

APPLICATION PROCESS

Any interested family can call the Easter Seal Society Orange County Regional Office to register in a Co-op. A short application form is sent to them along with an agency release of liability and a parent questionnaire. These are filled out and returned to the office to be used in the matching process. An in-home interview is then arranged with the family and the Respite Coordinator. If a Co-op already exists which suits their needs, they will be placed as soon as possible. If not, then a new Co-op will be formed when 5 other families with matching needs are recruited.

CONFIDENTIALITY

All information given at any time will be kept confidential at the Easter Seal Society Orange County Regional Office unless otherwise prearranged.

CO-OP CARE GROUP COUNCIL

The Care Managers elected from each Co-op will serve on the Council which will meet on a regular basis with the Respite Coordinator. They will discuss any problems, concerns, ideas for workshops, and otherwise be the voice of their Co-op group.

FIRST AID REQUIREMENTS

Due to the special needs of these children in the Co-ops, basic first aid skills are a must. This includes proper seizure training, what to do in an emergency or fire including an escape plan, and a valid CPR certificate. The Co-op members have up to three months after joining to take a qualified CPR certification course. The appendix includes more detailed first aid training.

HOME SAFETY CHECKLIST

The home-safety checklist is very important in order to assure parents their home is a safe environment for other children and that their son or daughter will be staying in an environment which is free from health hazards. Home accidents are a frequent cause of death and disability especially among children. However, many accidents are preventable with proper planning. The home-safety checklist is conducted by the parents themselves and is a list of minimum safety precautions which should be followed.

INACTIVE LIST

A family which does not utilize the Co-op for 60 days is considered "inactive". This does not remove them as members of their Co-op. A family may want to use the Co-op just for a summer vacation, or to have prearranged care in case of an emergency.

IN-HOME INTERVIEW

The Respite Coordinator conducts an introductory visit with each family. This visit is to discuss respite needs and availability, answer any questions which the new family may have, meet and get to know their children, and go over the home safety checklist. This interview will help the Respite Coordinator better match the individual respite needs of the family. When the family joins a Co-op they will receive a copy of the book "A Parent's Guide to the Respite Care Co-op" and the Respite Care Fact Packet.

INSURANCE

Homeowner's or renter's liability insurance is all that is needed to cover any accidents or injuries which may occur. At no time can money be exchanged for the care received or this liability is invalidated (California State Law #5801). Also automobile liability insurance is needed to transport the children at any time.

ILLNESS

When the sending family has prior knowledge of their child's illness, they must advise the caregivers at the time respite care is requested. Respite will be provided only if the caregiver is willing to do so. If a child gets ill during a respite care period, the caregiver must attempt to contact the parents. If an accident occurs, the parents must be contacted along with the Care Manager. An accident form must be filled out and returned to the Respite Coordinator. The child will have with him at all times a release of medical liability so proper medical attention can be given.

JOB DESCRIPTIONS

The jobs required in each Co-op consist of a Co-op Care Manager and a Recordkeeper. If prearranged, these positions may be filled by the same person. The job responsibilities are listed below:

Care Manager- will arrange substitute care if the family giving the care is unable to provide it during an assigned period or in case of an emergency. The Care Manager will collect accident forms and return these to the Respite Coordinator, represent the Co-op group while serving on the Co-op Council and be the voice for the Co-op group, help in the intake of new families into their Co-op by being a "host family", and will assist the Respite Coordinator with the planning and organizing of the workshops and training sessions. The Care Manager will earn extra hours for these duties and the job will rotate within the Co-op on a regular schedule.

Recordkeeper- will keep an accurate record of credit/debit hours and a balance for each Co-op. These hours will be reported to the Care Manager and Respite Coordinator at the end of every month. The Recordkeeper will also prepare a statement for each family at the end of every month and keep the Care Manager informed of any problems or discrepancies which may occur. The Recordkeeper will also earn extra hours for these duties and the job will rotate within the Co-op on a regular schedule.

Respite Coordinator- will be employed by the Easter Seal Society, Orange County Regional Office to organize the Respite Co-op. The Respite Coordinator will network potential Co-op members into care groups, organize trainings and workshops for Co-op members, meet with the Co-op Council periodically, and keep current all policies and guidelines and the parent's manual.

MEALS

If food is furnished by the family providing respite care, then each Co-op can arrange to credit 1/2 hour per meal for this family. Families may also include food, or a sack lunch, when sending their child for respite care.

MEDICATION

Medication may be administered by the caregivers if included in the Respite Care Fact Packet and/or written dated instructions are given to the caregiver at the start of the respite stay. All medications must be kept out of reach and in a safe place.

OVERNIGHT RESPITE CARE

For overnight care, a maximum amount of 17 hours can be earned per 24 hours of care unless otherwise prearranged. Examples of exceptions include infants who may not sleep through the night and if medication must be administered during the sleeping hours.

PUBLICITY

Respite services receive so little publicity that many people don't know what it is or how greatly it is needed. Parents who use respite programs need to especially "spread the word" and be a publicist for the program to recruit other families. Without publicity and support, respite services can be jeopardized and may be discontinued due to lack of exposure.

Sharing positive respite experiences is important in renewing the enthusiasm needed for quality respite services.

RECRUITMENT

Families interested in joining a Co-op can be referred by friends, parents, teachers, principals, social workers, doctors, etc. Getting people together who share common interests and similar needs is called "networking". Networking is especially important for the parents of children with special needs who are often alone in dealing with their day-to-day problems. A Respite Co-op network can help. To have successful groups that continue to meet regularly and bring in new members to keep the group lively and balanced is the key to successful, on-going Co-ops.

RECORDKEEPING

A ledger sheet will be kept by each Co-op member recording the credit, debit, and current balance. An official ledger will be kept by the Recordkeeper of each Co-op. A detailed account of respite hours is included at the end of this chapter under "Recordkeeping Policies". Copies of all ledgers will be kept on file at the Easter Seal Society, Orange County Regional Office. (See appendix for sample ledger).

REQUESTING RESPITE

A good motto for respite is "The longer you wait, the harder it is to get started." Remember that respite is designed to be used as prevention. Each Co-op member can call the families on their member's list to see who may be available. Usually one family will find two or three other families who are more convenient to trade hours with. After the care period, each family calls the Recordkeeper to report the credit and debit hours earned. The Recordkeeper will try to keep Co-op members informed as to which families are the most in debt. Whenever possible, members should try to call these people first when arranging respite care to help them earn credit hours in order to balance their account. A family may owe a maximum amount of 25 debit hours before they must give credit hours.

RESPITE CARE FACT PACKET

This fact packet contains all the information needed to care for the child. It must be filled out by the parents and kept with the child at all times. Parents must also leave the phone number of where they will be, phone numbers of doctor, police, fire, husband, and close neighbors, and a dated signed medical release.

SIBLINGS

Siblings may be cared for at the same time if their care will help rather than detract from the care of the child with special needs. Parents and caregivers should agree on whether siblings are included and the number of children to be cared for when arranging the respite period. Families with siblings, who are requesting care for them, will be placed into Co-ops with other families willing to care for siblings so these needs and requests will be met.

SUBSTITUTE CAREGIVERS

There shall be no substitute caregivers allowed due to the amount of training and high qualifications required unless it is otherwise agreed upon with the other members of the Co-op.

TRAINING SESSIONS

At training sessions, parents instruct each other on how to care for the unique and special needs of their child and also learn to care for the other children in their Co-op. This insures quality care by families specifically trained to care for each members' child.

TRANSPORTATION

Children may not be transported from the premises agreed upon except with the parents prior consent. If the child is transported, then automobile liability insurance is required. The California State Law requires that children under 4 years or 40 lbs. must be fastened in a secured car seat. By law, all other children are required to be fastened in a safety seat belt. Extra hours can be earned for transport if the caregiver otherwise would not have made the trip.

WORKSHOPS

Workshop sessions are provided periodically by the Easter Seal Society. Workshops involve bringing in professionals on various subjects such as behavior management, language and communication, wheelchair transfer, parent advocacy, etc. These subjects are suggested by individual Co-ops or by the Co-op Council. These workshops are held at convenient times for parents, such as evenings or Saturdays, with child care available.

WITHDRAWAL POLICY

A family may withdraw from the Co-op at any time after their hours are paid up. An exception might include a family moving from the area, or in a crisis or emergency. If a family wishes to withdraw, the arrangements should be discussed with both the Care Group Manager and the Respite Coordinator. A family may stay in a Co-op on an inactive list, if desired, in order to have respite available to them in times of emergencies.

RECORDKEEPING POLICIES

Listed below are the specific policies for recordkeeping of respite hours:

1. A 1/2 hour credit can be earned for transport if the caregiver would not have otherwise made the trip.

2. A 1/2 hour credit can be earned for meals unless the parent provides a sack lunch.

3. A total of 17 hours may be earned per 24 hours for overnight respite unless otherwise prearranged.

4. A family may not owe more than 25 debit hours at any one time before credit hours are given to lower their balance.

5. All quarter hours (15 mins.) will be rounded off to the nearest half hour. (Over 15 mins.= 1/2 hour).

6. A 1/2 hour credit can be earned per hour for each non-disabled sibling if their care will help rather than detract from the care of the child with special needs.

Example: 1 child = 1 hr. credit/ per 1 hr.
2 children = 1 1/2 hrs. credit/ per 1 hr.
3 children = 2 hrs. credit/ per 1 hr.

7. Co-op members may earn double (or triple, etc.) time by providing care for several members' children at the same time if agreed upon ahead of time by all members involved. Each parent is charged the regular debit hours and the member earns double (or triple, etc.) credit hours.

8. If the parents set a time for return, they must notify the sitter by telephone of any delay. The parent can be charged double time for any hours later than the agreed time of return unless otherwise decided.

9. If a child is picked up after midnight, then double time hours will be charged for the hours after midnight. (Example: 12:00 a.m.- 2:00 a.m. charged 4 hours debit).

10. A parent must notify the member giving respite care of a cancellation <u>at least</u> 4 hours before scheduled respite time. Any cancellation without proper notice, except for illness or emergency, gives 1 hour credit to the caregiving member.

11. Both the caregiving family and sending parents shall determine the official respite time to call into the Recordkeeeper so there will be no question or differences in the records.

Chapter 6

Be Creative!

CHAPTER SIX

BE CREATIVE!
"101 WAYS TO USE YOUR RESPITE TIME-OFF"

Some people may think it is strange to have to include ideas for parents on how to spend their time-off. We always find ourselves saying, "I have 101 things to do today!" But now the time is available. The most important thing to remember is be creative (and it doesn't have to always cost money). While the time away is good for the parent, it also offers the child a great opportunity to make new friends, become more independent, and learn new skills. Listed below are 101 ideas to get started.

1. enjoy a romantic weekend
2. see a movie with friends
3. go out to dinner alone
4. take a walk on the beach to watch the sunset
5. have a picnic in the park
6. go to a museum
7. take a long hot bath
8. join an exercise class
9. go back to school
10. try photography
11. walk your dog
12. lunch with a friend
13. read a good book
14. play a game of golf
15. do your housecleaning
16. sew, knit, or crochet
17. see an opera
18. take up jogging
19. go to a baseball game
20. see a play
21. barbecue with neighbors
22. attend a wedding
23. go Christmas shopping
24. find a new hobby
25. take a helicopter ride
26. try bike riding
27. join a parent's group
28. go to church
29. sunbathe
30. plant a garden
31. attend a conference
32. shop for new clothes
33. get your haircut
34. watch football on TV
35. get a part-time job
36. spend time with your other children
37. mow the lawn or do some gardening
38. see the ballet
39. go to a company party
40. play tennis
41. learn how to sail
42. go to Las Vegas
43. attend an open house
44. go fishing
45. watch a dance recital
46. volunteer
47. go to the dentist
48. go to the doctor
49. visit the library
50. vote
51. go to a city council meeting
52. visit a sick friend
53. go to a class reunion
54. interview for a job
55. attend a seminar
56. wallpaper a room
57. learn to ski
58. build a sand castle
59. take a cooking class
60. paint your house
61. do nothing
62. go to a sports event
63. enjoy a concert
64. play racquetball
65. rest in the jacuzzi
66. watch a fashion show
67. enjoy New Year's Eve
68. take flower arranging

69. go wine tasting
70. try marriage encounter
71. ride in a hot-air balloon
72. try hang-gliding
73. visit out-of-town relatives
74. see an antique show
75. grocery shop
76. go bowling
77. tour a design home
78. get your banking done
79. build something
80. go camping
81. go hiking
82. join a club
83. listen to music
84. take a long cruise
85. take a dance lesson
86. tune-up the car
87. go horseback riding
88. go 4-wheeling
89. sell real estate
90. start your own business
91. roller or ice skate
92. write a book
93. write a poem
94. compose a song
95. go to the swap meet
96. travel
97. polish your silver
98. try a new restaurant
99. take flying lessons
100. SLEEP!
101. Be creative! I'm sure you can think of 101 more!

Remember the idea is to be as creative as possible using the time wisely. Some parents say they have not had an evening alone together in the last two, three, even four years. Why wait another four? Respite is a necessity-and a right-which every parent of a child with special needs should have in order to continue a happy and productive life. Why not give it a try today? Make that call and start enjoying some earned "time-off".

Appendix

APPENDIX

EXAMPLE OF RESPITE LEDGER

1. A ledger sheet will be kept for each family in a Co-op to record debit hours (care received) and credit hours (care given) and a current balance.

2. Each family will keep their own record of hours and the Co-op Recordkeeper will keep the official record for each Co-op.

3. Each family contacts the Recordkeeper, whether reporting credit or debit hours, for the official ledger. Every month the Recordkeeper will balance the respite ledger and inform each family of their monthly balance.

4. Listed below is an example of a ledger for one family. A checkmark in the credit or debit columns indicates that these hours have been recorded on the other family's ledger.

NAME:	Adams, Mark & Joan	(714) 545-2035			
Date Called	DEBIT-Request made for	CREDIT-Request accepted by	HOURS Debit	Credit	Balance
6/8	Care on 6/7 Fri. 6:30-9:00 pm	By Cindy & Bob Smith	-2.5	✓	-2.5
6/9	Care on 6/8 Sat. 9:00 am -2:00 pm	By Maggie & John Crane	-5.0	✓	-7.5
6/10	Care for Ted & Norma Jones	Care on 6/9 Sun. 4-10:00 pm	✓	9	+1.5
6/20	Care on 6/19 Wed. 5:30-10:00 pm	By Linda & Jim Upton	-4.5	✓	-3.0
6/22	For Maggie & John Crane	Care on 6/22 Sat. 9:00 am-5:00 pm	✓	8.5	+5.5
6/30	Monthly Totals		-12	+17.5	
		Balance			+5.5

APPENDIX

FIRST AID TRAINING: "BE PREPARED"

There is a detailed account of basic first aid training found in the front pages of the local Telephone White Pages, including information on choking, burns, broken bones, heart attacks, and what to do before, during, and after an earthquake.

The 911 telephone number has been developed to quickly summon emergency service in an crisis or emergency situation. Below are listed some basic treatment procedures of the problems most likely encountered.

Cardiopulmonary Resuscitation (CPR)- CPR is a skill required to keep someone alive if their breathing and heartbeat have stopped. Both the American Red Cross and the American Heart Association offer a certification program. Also your local fire department will generally offer instruction to residents of their city. CPR certification is required of all Co-op members after three months of membership.

Mouth-to-Mouth Resuscitation- Lack of breathing should be the first concern in any unconscious or seriously injured person. If the person is not breathing, pinch the nostrils with the thumb and forefinger, open the mouth wide and seal it over the victim's mouth, and then blow the air from your lungs into the victim's mouth. Continue this process at a rate of once every five seconds for an adult and once every three seconds for a child.

Poisoning- Small children are most often the victims of accidental poisoning. If a child has swallowed or is suspected to have swallowed any substance that might be poisonous, assume the worst and TAKE ACTION! Contact your local Poison Control Center (UCI 101 The City Dr. Orange 634-5988) for further instructions or for more information for the particular substance. You can also call 911 for emergency help. The victim should be transported to a medical facility and any containers or a sample of the vomit should be saved.

Bleeding- Bleeding can usually be controlled by applying pressure directly to the wound. Apply firm, steady direct pressure for 5-15 minutes. Severe nose bleeding can often be controlled by

direct pressure such as by pinching the nose with the fingers. Apply direct pressure for 10 minutes without interruption. If the bleeding persists take the victim to a medical facility.

Burns- For first degree, the skin is reddened; second degree, blisters form; and third degree, the skin is destroyed and underlying tissues are damaged. For first and second degree burns, cool the area by immersion in water or application of cold compresses. When the area is cool to the touch, cover with a sterile dressing. For a third degree burn, cover with a loose sterile dressing and seek medical attention. Do not use butter or creams in the treatment of a severe burn.

Seizures-The general principles of first aid for someone who is having a seizure are: 1) protect the individual from physical harm during the seizure, 2) position the head, if possible, to assure an open airway, 3)turn the individual onto his side if possible, 4) do not try to restrain the victim, 5) let the seizure run its course and record the details if possible, 6) do not place anything in the victim's mouth at any time. After the seizure the victim may be confused and very tired. Allow them enough time to rest quietly.

APPENDIX

RESPITE CARE CO-OP MEMEBERS:
"BE A PART OF IT"

RESPITE COORDINATOR
Address
City
Phone

CARE MANAGER
Address
City
Phone

RECORDKEEPER
Address
City
Phone

MEMBER'S NAME
Address
City
Phone

MEMBER'S NAME
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Parents Bill Of Rights

Freedom to feel that they have done the best they could

Freedom to enjoy life as intensely as possible, even though they have an exceptional child

Freedom to let their handicapped child have privacy

Freedom to have hostile thoughts once in a while without feeling guilty

Freedom to enjoy being alone at times

Freedom to tell people about their child's progress and achievements with a real sense of pride

Freedom to have their own hobbies and interests

Freedom to tell teachers and other professionals what they really feel about the job the professionals are doing and demand that their opinions be respected

Freedom to devote as much time as they want to the handicap cause; to get away from it for a while and return if they want

Freedom to tell their child when they are displeased with the child, even though their child has a handicap.

Freedom to refrain from praising their child gratuitously, even though they have been told to offer much praise.

Freedom to lie once in a while and say everything is fine; not to feel compelled to tell the truth to everyone who asks

Freedom to say at times that they do not want to talk about their problems or their handicapped child

Freedom to spend a little extra money on themselves, even though they feel they cannot afford it

Freedom to have an annual vacation without the children, to have dates, celebrations, weekends away, and time together to enhance their marriage

Gordon 1975

APPENDIX

EXAMPLES OF RESPITE FORMS

Dear Parent,

Thank you for expressing an interest in the Easter Seal Society Respite Care Co-op. We are very pleased to provide this service to you. Enclosed you will find a packet which consists of the following: Parent Registration Form; Parent Questionnaire; and Agency Liability Release. These need to be completed and returned back to us in the stamped, self-addressed envelope provided. The two brochures are for you to keep for your information.

After reviewing these materials, a coordinator will contact you in order to arrange a In-Home Visit. At this visit we will bring the Parent's Handbook and the Home-Safety Checklist that we will go over with you. This visit will also allow us to answer any questions you may have at this time. By getting to know you and your family better, we hope to match your respite needs more carefully with other co-op families.

When this registration process is completed, we will help you to become acquainted with the other families in your co-op group. Then you're ready to begin exchanging respite hours.

Please don't hesitate in sending back the completed forms. We'll be looking forward to hearing from you soon.

Most Sincerely,

Lori Shaw & Tonya Gallegos

Respite Coordinators

Enclosure

EASTER SEAL SOCIETY

RESPITE CARE CO-OP

PARENT/FAMILY REGISTRATION DATE_____

I. Applicant

Child's Name_____

Address_____

City_____ Telephone_____

II. Parent's Information

A. Father's Full Name_____

Address(if different than child's)_____

City_____ Telephone_____

Place of Employment_____

Job Position_____ Telephone_____

Hours Usually Worked_____

Time(distance) to work_____

B. Mother's Full Name_____

Address(if different than child's)_____

City_____ Telephone_____

Place of Employment_____

Job Position_____ Telephone_____

Hours Usually Worked_____

Time(distance) to work_____

C. Other people living in child's home

Name_____ Age_____

Name_____ Age_____

Name_____ Age_____

Name_____ Age_____

III. Child's Information

Diagnosis/Disability_____

Birthdate_____ Age_____

Height_____ Weight_____

Religion_____ Language_____

School Attended_____

Address_____

Child's information Continued

Doctor_____ Telephone_____

Seizures? (frequency)_____

_____

Special Equipment Needed?_____

_____

Behavior Problems? (explain)_____

_____

Other Concerns?_____

_____

_____

IV. Information on Respite Needs

How often will you need respite (estimate)?_____

_____

How many hours apprx. will you need a week?_____

_____

What days- weekends, weekdays, evenings?_____

_____

How do you feel about your child in another home?_____

_____

How do you feel about another child in your home?_____

_____

Do you have Homeowner's or Renter's Insurance?_____

Company/Policy #/Exp. Date_____

Do you have Automobile Liability Insurance?_____

Company/ Policy #/ Exp.Date_____

****

This form is kept confidential by the respite coordinator and is used in the matching process. A more detailed Respite Fact Packet is filled out by the parents and kept with the child during all respite care periods.

DATE_____ _____

RESPITE CARE CO-OP
PARENT QUESTIONNAIRE

Please circle the corresponding number that best fits your response to the questions below.

0	1	2	3	4	5
not applicable	strongly disagree	disagree	neutral	agree	strongly agree

I. I AM INTERESTED IN THE PARENT RESPITE CO-OP BECAUSE I NEED OR WANT...

1. more time with my husband or wife.

   0 1 2 3 4 5

2. more time with my non-disabled children.

   0 1 2 3 4 5

3. more time alone for rest and relaxation.

   0 1 2 3 4 5

4. to get to know and share with other parents of disabled children.

   0 1 2 3 4 5

5. the opportunity to help other families with their much needed relief time.

   0 1 2 3 4 5

6. new experiences and social contacts for our disabled child.

   0 1 2 3 4 5

7. the opportunity for our non-disabled children to interact with other families with disabled members.

   0 1 2 3 4 5

8. people specifically trained to care for my disabled child.

   0 1 2 3 4 5

9. extended respite care without cost.

   0 1 2 3 4 5

10. other (please explain) _____.

NAME AND ADDRESS_____

AGENCY RELEASE OF LIABILITY

I (We) hereby release and discharge the Easter Seal Society of California, Orange County Regional Office, and its employees, volunteers, and directors from any liability as a result of co-ordinating respite care services for my (our) child(ren) _____.

I (We) further agree to indemnify and hold harmless the Society from any loss, liability, damage, or costs that may be incurred during the respsite care period.

I (We) have fully disclosed to the staff of the Easter Seal Society of California, Orange County Regional Office, all pertinent facts about my (our) child(ren)'s needs and problems and acknowledge full responsibility for failure to do so.

_____

Parent/Guardian

_____

Date

EMERGENCY MEDICAL RELEASE

I (We) the parent/guardian of _____ authorize _____ (Respite Caregiver's name) to act on behalf in the event such child or adult is the victim of accident, injury, or illness necessitating immediate medical, surgical or dental care, but only after the above-named individual has made an effort to notify me of such an emergency situation.

I (We) authorize the above-named individual to use his/her best judgement in making a determination that an emergency exists, in seeking approriate medical or dental treatment and in giving his/her consent to such treatment in my absence.

I (We) absolve the above-named individual, and nurses, physicians, and surgeons selected and designated by them from any and all liability for their acts rendered in good faith.

CAREGIVER'S RELEASE OF LIABILITY

I (We) hereby release and discharge _____ (Respite Caregiver's name) from any liability as the result of his/her care for my (our) child(ren) _____. This agreement is specifically meant to release the above-named individual from any legal liability for injuries suffered by my (our) child(ren) caused by the supervision or care given my (our) child(ren) in a respite care situation. This agreement is not meant to be a release of legal liability for intentional injury to my (our) child(ren).

_____

Parent/ Guardian

_____

Date

EASTER SEAL SOCIETY

RESPITE CARE CO-OP

ACCIDENT FORM

Name of Injured Person_____ Age _____

Family Name_____

Address_____

City_____ Telephone_____

Name of Person Reporting_____

Address_____

City_____ Telephone_____

****

Date of Accident_____ Time_____

Place(please be specific)_____

_____

Describe Incident _____

_____

_____

Were the parents notified?_____ Date and time_____

Instructions_____

Was the Care Manager notified?_____ Date and time_____

Instructions_____

Was a Doctor notified? Who?_____ Date and time_____

Instructions_____

Was First Aide needed/given?_____

_____

Was hospitalization needed? _____

_____

****

Signature of Person Reporting_____ Date_____

Signature of Parent_____ Date_____

****

Copy to parent, Care Manager, and Respite Coordinator.

6. Are infants and toddlers' toys soft and the individual parts too large to be swallowed?

7. Are used plastic bags destroyed or kept out of children's reach?

8. Do all family members refrain from smoking in bed?

neck your bathroom to eliminate all opportunity for acci-ental falls, poisoning and scalding...

s	no
1. Are non-skid mats used in bath tubs and shower?	
2. Are all medicines kept in locked cabinets out of the reach of children?	
3. Are medicines for "external use only" labeled as such and kept separate from others?	
4. Do you discard prescription drugs after their use has ended?	
5. Have handgrips been installed alongside the shower, tub and toilet, especially if bathroom is used by elderly or handicapped persons?	
6. Are infants and toddlers watched at all times when in tub?	
7. Are all electrical appliances kept away from water and unplugged after use?	

o see if your yard is as safe your home, answer the llowing questions...

s	no
1. Are steps and sidewalks kept free from ice, snow, toys, tools and debris?	
2. Is yard free from glass, nails, yard tools and all items with jagged edges?	
3. Are garden sprays non-poisonous?	
4. Is play apparatus checked regularly?	

5. Are clotheslines strung high enough to clear pedestrian traffic?

6. Are children kept from playing in streets and driveways?

7. Do you use charcoal lighter fluid—never gasoline—to light your outdoor grill?

8. Are children kept away from power mowers, hedge trimmers and snow blowers when such appliances are being operated?

9. Does person operating power mower wear sturdy shoes?

10. Do you limit the time you work in the hot sun?

Check your safety score...

A "yes" answer indicated a high level of safety consciousness in each question area. Each "no" answer indicated a potential hazard to your family's safety.

Create a safety climate in your home by rechecking each "no" answer and removing all hazards.

Easter Seals®

prepared as a public service
by
THE NATIONAL EASTER SEAL SOCIETY

182-117

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A-210

Home Safety Round-Up

A Family Checklist...

Home accidents take the lives of more than 20 thousar Americans each year. Additionally, some 3½ millic persons are disabled as the result of accidents occurring the home—a figure almost twice as high as that reflecti injuries on the nation's highways.

Home can be one of the most dangerous places for you ar your family today unless you take the time to read an follow the simple safety hints that can make yours an acc dent-free home.

The National Easter Seal Society, in an effort to help cu down on the number of crippling injuries occurring in hom accidents, has prepared this checklist to help you spc potential hazards that may exist in your home.

Check the following throughout your home...

yes	no	
		1. Are electrical extension cords in good condition?
		2. Are electrical extension cords kept from being stretched across heavily travelled areas of your home?
		3. Are unused electrical outlets covered or locked?
		4. Are electrical outlets checked regularly for overloading?
		5. Do you know how to turn off gas and electricity in case of an emergency?
		6. Are proper size fuses used for replacement rather than pennies or substitutes?
		7. Are floor surfaces non-skid?
		8. Are all floor coverings fastened down?
		9. Are fireplaces screened and protected?
		10. Is an approved fire extinguisher kept on each floor?
		11. Are open flames such as candles kept away from walls and curtains?
		12. Do you have emergency phone numbers—police, fire, doctor, utilities—handy to the phone?
		13. Are frequently used items stored within safe, easy reach of adults?
		14. Is a sturdy stepladder available for climbing?
		15. Do interior doors such as those on closets or bathrooms have safety release locks that allow them to be opened from either side?
		16. If there are small children in your home, are open windows securely screened?
		17. Is lead-free paint used on all objects accessible to children?

Stairs and hallways may offer serious dangers to your family. Protect your family and friends by eliminating all hazards...

yes	no	
		1. Are stairway approaches kept uncluttered and free of throw rugs?
		2. Do stairways have strong bannisters or railings?
		3. Are all steps in a flight the same height and width?
		4. Are steps kept free of toys, tools and other objects?
		5. Are stair treads or carpeting kept in good repair?
		6. Is the stairway well-lighted with electrical switches located at top and botton?
		7. Are young children protected by gates placed at the top and bottom of stairways?
		8. Are nightlights provided in hallways and bedroom-bathroom areas?

Keep your kitchen safe for you and your family by checking for the following...

yes	no	
		1. Are window curtains out of the reach of the stove?
		2. Are electrical appliances disconnected when not in use?
		3. Is there a light over stove and sink?
		4. Do gas appliances have flue ventilation?
		5. Are freezer units and trash compactors locked to protect children?
		6. Are furnaces and flues inspected regularly?
		7. Are drawers and cupboards kept closed?
		8. Do you keep knives in rack or compartment tray?
		9. Are pan handles pointed away from the edge the stove and other burners?
		10. Are all cleaning agents kept on shelves abo children's reach?
		11. Are grease, water, and other spilled liquids foods wiped up immediately?
		12. Do you have hot dish holders near stove?

The bedroom is the site of a very high percentage of deaths due to home accidents. To keep your family safe, sure no safety hazards exist in your bedrooms.

yes	no	
		1. Is a light within easy reach of the bed?
		2. Are room heaters turned off at bedtime?
		3. Do you keep your room properly ventilate when using a room heater?
		4. Is your infant's mattress firm and bed free c pillows and loose blankets?
		5. Are small children's clothes checked for pir and detachable decorations which could b swallowed?

Easter Seal Society
Orange County Regional Office
151 Kalmus Drive, Suite F-3
Costa Mesa, CA 92626

POSTAGE REQUIRED IF MAILED

The Easter Seal Society is the country's oldest non-profit health care agency providing direct services to people with disabilities. These services - tailored to meet existing community needs - include information, referral and follow-up, transportation, equipment loan, camperships, toddler safety car seat rental program, purchase programs towards rehabilitative services, respite program, Saturday fieldtrip program and vocational scholarships.

Easter Seals
SERVING THE HANDICAPPED

The Easter Seal Society Respite Care Co-Op is supported by grants received from the Regional Center of Orange County, Inc. and the City of Orange.

Respite Care Co-Op

Easter Seals

WHAT IS IT . . .

WHY YOU NEED IT . . .

HOW TO GET IT . . .

R Relief for parents of children with special needs.

E Exchanging credit & debit hours of care.

S Support and understanding from other families.

P Parent-run program

I Innovative alternative in Orange County

T Time for rest, relaxation & recreation

E Easter Seal Society
Orange County
Regional Office

WHAT IS IT . . .

The respite care co-op is a program designed to assist families with short-term regular or crisis relief time. Each family will be matched with no more than ten other families who share similar needs and geographic location. A parent's handbook and on-going training sessions will be provided. There is **no cost** for this program. The care received is paid for by an equal amount of care given.

WHY YOU NEED IT . . .

It is **OKAY** for parents to take regular time away from their child, disabled or not!! Friends, personal interests and time alone can be the best therapy in the world. A dinner or movie with your spouse, an hour to shop, or take a hot bath, time for a doctor appointment, or even a whole weekend for business or pleasure. You return rested with more energy, enthusiasm, and patience to care for your child's special needs.

HOW TO GET IT . . .

For more information return the form provided or call us directly at (714) 545-2033.

Yes, I would like more information on the Parent Respite Care Co-Op.

Name _____

Address _____

City _____ Telephone _____